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SMS messaging to improve ART adherence: perspectives of pregnant HIV-infected women in Kenya on HIV-related message content

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Abstract

There is growing evidence that mobile health (mHealth) approaches including short messaging service (SMS) can improve antiretroviral therapy (ART) adherence, but consensus is lacking regarding communication of HIV-related information. Most interventions to date have delivered SMS that do not overtly refer to HIV or ART in order to avoid risk of status disclosure. In formative work for an ongoing randomized controlled trial (RCT) evaluating one-way and two-way educational SMS for prevention of mother-to-child-transmission (PMTCT) adherence in Kenya, we conducted 10 focus group discussions (FGDs) with 87 HIV-infected peripartum women to determine desirability and preferred terminology of HIV-related content. SMS for the RCT were developed based on FGD findings. Roughly half of FGD participants supported receiving SMS containing overtly HIV-related terms, such as 'HIV' and 'medication', citing desire for detailed educational messages about ART and PMTCT. Those opposed to overt content expressed concerns about confidentiality. Many participants argued that acceptability of HIV-related content depended on the recipient's disclosure status and others' access to her phone. Based on these findings, both covert and overt SMS were developed for the RCT and participants who owned their phone or had disclosed their HIV status to anyone with access to their phone were able to choose one of three options: (1) covert SMS only, (2) overt SMS only in response to HIV-related questions from the

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participant, (3) overt SMS routinely, initiated by the study. Of the 825 participants in the RCT, 94% were eligible to receive overt SMS. Of these, 66% opted to receive routine overt SMS and 10% to receive participant-initiated overt SMS. These findings show there may be interest in overt HIV-related information by SMS when risk of status disclosure is low, and support use of messaging strategies that allows participant choice in HIV-related content while protecting against undesired disclosure.

Keywords

HIV; SMS; confidentiality; education; adherence; Kenya

Introduction

There is growing evidence that short messaging service (SMS) messages sent to HIV-infected individuals can improve adherence to antiretroviral therapy (ART) (Kanters et al., 2017; Mayer & Fontelo, 2017; Mills et al., 2014; Thakkar et al., 2016). The most efficacious SMS content and phrasing for improving ART adherence has not been determined; efficacious SMS interventions vary significantly in structure, content and hypothesized mechanism of action. They include simple reminders (Pop-Eleches et al., 2011), greetings intended to open dialogue and identify patient challenges (Hardy et al., 2011; Lester et al., 2010), educational content to catalyze behavior change (Mbuagbaw, Thabane, Ongolo-Zogo, Lester, et al., 2012b), and content composed by the patient themselves, which may employ any of these approaches (Haberer et al., 2016).

Concerns regarding SMS privacy have raised questions about how HIV-related information should be communicated to balance potential benefits of delivering clear, detailed information against risks of HIV status disclosure (Pérez, Hwang, Bygrave, & Venables, 2015). Some qualitative studies have reported that SMS recipients desired discreet, coded messages to prevent status disclosure (Curioso et al., 2009; Rana et al., 2015), while others reported a lack of consensus among recipients (Mbuagbaw, Bonono-Momnougui, & Thabane, 2012a), and desire by some for detailed information about HIV medication (Georgette et al., 2016). Most interventions to date have delivered SMS that do not overtly refer to HIV or medication, instead sending greetings (Lester et al., 2010), indirect reminders to 'take care of health' (da Costa et al., 2012; Pop-Eleches et al., 2011), or unrelated content such as news, weather or jokes (Hardy et al., 2011). A few studies have used messages referencing 'medication', but not 'HIV' (Georgette et al., 2017; Mbuagbaw et al., 2015; Schwartz et al., 2015). To date, one intervention (South Africa's *MomConnect* program, which has >500,000 subscribers) includes overt HIV-related SMS in its educational content (Barron, Pillay, Fernandes, Sebidi, & Allen, 2016; Mobile Alliance for Maternal Action, 2014). Design of HIV-related communication in SMS interventions is influenced by the intervention's theoretical basis, and also by what is acceptable and ethical in the study population. When SMS are sent as medication reminders, coded language likely suffices to impact adherence, and has the benefit of reducing the risk of status disclosure. However, for interventions seeking to facilitate behavior change through education or support mechanisms, this strategy limits the potential of SMS to communicate HIV-related

information or address HIV-related challenges, and may thus reduce the intervention's efficacy.

The ongoing *Mobile WACHX* randomized controlled trial (RCT) evaluates the impact of weekly SMS on ART adherence in Option B+ prevention of mother-to-child-transmission (PMTCT) in Kenya, comparing one-way SMS (receiving messages from the study only), versus two-way SMS (including the ability to respond and engage in conversations with the study nurse), versus control (no SMS) (Drake et al., 2017). The SMS intervention, based on the Health Belief Model (Janz & Becker, 1984), is designed to provide tailored and actionable education, social support and reminders. Clarity of the message content may influence the impact of the intervention. Maintaining privacy was central to the intervention's design, but exploring the acceptability of HIV-related messaging was important for optimizing SMS development. In formative work for the RCT, we conducted focus group discussions (FGDs) with HIV-infected pregnant and postpartum women to determine HIV-related communication preferences. Here we present FGD findings, the final messaging strategy developed for the RCT, and data on HIV-related message uptake by RCT participants.

Methods

Prior to SMS development for the *Mobile WACHX* trial, ten formative FGDs were conducted in the communities where the RCT would take place: 6 in the Nyanza region and 4 in Nairobi. Each FGD included 6-10 participants. Participants were purposively sampled from antenatal or HIV care facilities at 3 RCT study sites and included women who were HIV-infected, 14 years old, pregnant or had an HIV-uninfected child 2 years old, willing to receive SMS, literate or had someone who could assist with reading SMS, and had daily access to a mobile phone. All participants provided written informed consent for FGD participation.

FGDs were conducted in private rooms at the clinics from which participants were recruited (two clinics in the Nyanza region and one in Nairobi) and were facilitated by a female Kenyan social scientist trained in qualitative research methods and fluent in English, Kiswahili and Dholuo, the dominant languages at the study sites. FGDs were conducted in the participants' preferred language, and explored women's experiences with ART, perspectives on the use of SMS to support HIV care and SMS topics of interest through open-ended questions and discussion of acceptability and comprehension of example SMS (see FGD guide in Supplementary Material 1). Probing assessed desirability of HIV-related content and sought suggestions for SMS composition. FGDs were audio-recorded and verbatim transcripts generated and translated into English by the facilitator. Transcripts were analyzed using Dedoose version 7.0.23 (www.dedoose.com). This manuscript focuses on participants' attitudes to HIV-related content. Analysis of other FGD themes is reported elsewhere (Fairbanks et al., 2017).

Following SMS development, RCT participants were recruited from 6 public antenatal care clinics and assigned to one-way SMS, two-way SMS or control arms by concealed randomization using variable block sizes as described in (Drake et al., 2017). Eligible

participants were pregnant, HIV-infected, age 14 or older, had daily access to a mobile phone with a Safaricom SIM card, and planned to reside in the area for 2 years and receive their HIV and postnatal care at the study facility where they were recruited. SMS were sent and received by participants free of charge, using a short code. Participants' HIV messaging preferences, including changes post-enrollment, were recorded through the study SMS management system. All participants provided written informed consent for RCT participation.

Study approval was obtained from ethical review committees at University of Nairobi / Kenyatta National Hospital and University of Washington.

Results

Eighty-seven women participated in FGDs. A little over half (56%) of participants were from Nyanza sites. The median participant age was 26, 73.6% had completed primary education, 65.5% were postpartum and 69.0% had used ART for their own health as well as PMTCT (Table 1).

Participants were asked whether they thought women would want to receive SMS that overtly mention HIV, HIV-related terms, or words such as 'medication' and 'infection', which may arouse suspicion in someone unaware of the recipient's HIV status. Across all FGDs, approximately half of participants responded that this would be desired. The proportion favoring overt SMS varied by region: in Nyanza, the majority of participants were in favor, while in Nairobi the majority opposed it.

Participant rationale in favor of overt HIV-related content

Participants favoring HIV-related content commented that it would strengthen treatment knowledge and motivation:

"You will know how to take your medication" (20-year-old, pregnant, Nyanza group 5)

"We will be motivated in areas that we are weak" (39-year-old, postpartum, Nyanza group 2)

Many participants expressed a desire for educational SMS about ART side effects, modes of MTCT and infant prophylaxis – topics difficult to adequately discuss using covert language:

"They should let you know of possible side effects of certain drugs by SMS so that when you see such effects you come to the clinic immediately for help." (18-year-old, pregnant, Nyanza group 4)

"I would like to know what I can do so that my child is born negative and how to take care of him so that he grows up HIV negative." (39-year-old, pregnant, Nyanza group 4)

"I wish to know: the baby is tested thrice, now if it is tested and found negative will it stay negative or will the disease come back later on? That is really disturbing me." (43-year-old, postpartum, Nyanza group 4)

Concerns regarding overt HIV-related content

Of those who did not support HIV-related content, many expressed concerns about confidentiality:

“You can send the message when I have given out my phone to someone who doesn’t know my status so if they read that message they will know my status and I think that...is not good” (26-year-old, postpartum, Nairobi group 2)

“At times you go somewhere and the SMS beeps and one of your friends reads it, they might start despising you because... [they] have the old mentality that those who are HIV positive should be isolated. Some people are not free with persons who are HIV positive and that may cause stigma.” (18-year-old, pregnant, Nyanza group 4)

Phone sharing, disclosure, message directionality and wording influenced attitudes to HIV-related content

Many participants argued that acceptability of HIV-related content depended on the recipient’s disclosure status and accessibility of her phone to others:

“It depends on whether the phone is mine or my spouse’s... if the phone is mine then it’s fine... if it’s his and we have disclosed then it’s fine... if we haven’t then it’s a problem” (36-year-old, postpartum, Nairobi group 1)

Additionally, most participants made a distinction between receiving and sending HIV-related SMS. Almost all said women would feel comfortable sending HIV-related SMS to a provider, including women who opposed receiving them:

“We can [send] because the message is going out, it isn’t coming in” (37-year-old, postpartum, Nairobi group 2)

Participants provided guidance on acceptable HIV-related terminology. They generally preferred the terms ‘medication’, or ‘dawa’ in Kiswahili, rather than ‘ART’, ‘HIV medicine’, or the Dholuo slang term ‘andila’. Similarly, ‘infection’ was more acceptable than ‘HIV’.

RCT messaging strategy and participant preferences

Based on the FGD findings that participant preferences varied, we developed a strategy to provide participants with choice over HIV-related content and allow for overt HIV-related SMS if specific eligibility criteria were met. Both covert and overt HIV-related SMS were developed for the RCT (Table 2). Participants who had their own phone or had disclosed their HIV status to anyone with access to their phone were eligible to choose to receive overt HIV-related SMS; participants not meeting this definition received covert messages only. Eligible participants could select one of three options: (1) receive covert SMS only, (2) receive overt SMS routinely, initiated by the study SMS system (system-initiated HIV content), or (3) receive overt SMS only in response to HIV-related questions sent by the participant (participant-initiated HIV content). The third option applied only to participants randomized to the two-way SMS arm and was intended to allow the participant to control when HIV-related topics were discussed overtly. In this option, routine weekly SMS sent by

the study system contained covert language, but the nurse was permitted to respond overtly to an overtly HIV-related participant question. Prior to enrollment and randomization, participants were provided with example overt and covert SMS to help inform their decision. All participants provides written consent for this choice. The informed consent process involved detailed discussion of potential risks and benefits of receiving HIV-related SMS. Participants could modify their selection at any time.

Demographic characteristics of the 825 RCT participants are summarized in Table 3. Participants had a median age of 27, median time since HIV diagnosis of 2 years, and 76.8% had completed primary education. Six hundred and forty participants (78.6%) had disclosed their status to anyone with access to their phone and an additional 131 (15.9%) did not share their phone, for a total of 771 (93.5%) eligible to receive overt HIV-related SMS. Of these, 241 (31.3%) chose covert SMS, 510 (66.1%) chose system-initiated overt SMS, and 74 (9.6%) chose participant-initiated overt SMS. Eleven participants (1.9%) who initially selected to receive system- or participant-initiated overt content altered their selection to a more restricted setting after enrollment.

Discussion

There is growing evidence that SMS approaches can improve ART adherence, but there is no consensus in the field regarding SMS content, particularly the degree to which HIV can be overtly discussed by SMS. Most SMS interventions to date have employed covert communication strategies, in which indirect greetings, reminders or entertainment are used as means of initiating contact or reminding participants (da Costa et al., 2012; Hardy et al., 2011; Lester et al., 2010; Pop-Eleches et al., 2011).

In this study, in preparation for an ongoing RCT, we conducted formative focus group discussions with pregnant and postpartum women in Nairobi and Nyanza regions in Kenya to determine their preferences regarding communication of HIV-related information by SMS. We found that women differed in their attitudes to receiving SMS containing language that could divulge the recipient's HIV status, such as "HIV", "infection", "medication" and "ART". While some participants were opposed to use of these terms due to confidentiality concerns, many felt that they were acceptable if the recipient had disclosed their HIV status or had their own phone, and highlighted their value in communicating HIV-related educational information. These findings are consistent with previous findings that SMS content preferences and privacy concerns differ between individuals (Georgette et al., 2016; Mbuagbaw, Bonono-Momnougui, & Thabane, 2012a), likely due to differing experiences of stigma. We found that attitudes to overt HIV-related content differed by geographic region, with a greater proportion of participants in Nairobi opposed to overt content than in Nyanza. This may reflect differing concerns in Nyanza, a high-prevalence rural region, versus Nairobi, a moderate-prevalence urban region (National AIDS and STI Control Programme (NAS COP) Kenya, 2014).

The approach developed for our ongoing RCT, in which participants who had either disclosed their HIV status or had their own phone could opt to receive overt HIV-related content, contrasts with the covert content more commonly delivered in SMS interventions to

date. In interventions such as ours, where communicating educational messages is a goal, this approach offers a model for allowing intervention recipients to choose whether they receive overt HIV-related SMS based on their individual preferences and situation, while including protections against HIV status disclosure. In particular, the option to receive overt messages only as responses to patient-initiated SMS affords patient control in the context of two-way messaging. Consistent with the views expressed in the FGDs, of 771 participants given the option to receive overt HIV-related SMS in the RCT, around a third (31.3%) chose to receive only covert SMS, while most (66.1%) chose system-initiated overt SMS, and 9.6% chose participant-initiated overt SMS. Notably, few (1.9%) participants modified their HIV messaging preferences to a more restricted setting after enrollment.

This study should be interpreted in light of its limitations. Our findings may not be generalizable to groups other than pregnant and postpartum women or settings outside of the regions of Kenya we sampled. Additionally, our study explored recipients' concerns about status disclosure due to third party access to their phone; it did not probe their concerns about telecommunications providers accessing messages during transmission. Importantly, our findings speak only to participant preferences, not to the efficacy of overt or covert HIV-related SMS to improve treatment outcomes. Despite these limitations, our study suggests that, for SMS interventions seeking to communicate educational content where information clarity is important, overt HIV communication may be acceptable to some individuals, provided adequate protections exist against undesired HIV status disclosure. The messaging approach employed in our RCT can serve as a model for achieving this in future similar studies.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Demographic characteristics of focus group discussion participants

n (%) or median (IQR)	
N=87	
Age (years)	26 (23-32)
Pregnant (vs. postpartum)	30 (34.5)
ART experience	
PMTCT only	19 (21.8)
PMTCT & own health	60 (69.0)
No ART Experience	8 (9.2)
Primary education completed	64 (73.6)
Location	
Nairobi	38 (43.7)
Nyanza	49 (56.3)

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Table 2

Example covert and overt HIV-related SMS

Topic	Covert message	Overt message
Adherence	Your health is very important. Take time each day for your health.	Remember that HIV medications keep you healthy and prevent your baby from being infected. We are here to help.
Adherence	Make sure to take time each day for your health.	Make sure to take your medications every day. If you have someone you trust, you can ask them to help remind you.
Adherence at cessation of breastfeeding	Your health is very important for you and your baby, even as your baby grows. Continue to take time each day for your health.	Even if you are breastfeeding less, you and your baby still need your HIV medications. Continue to take them each day.
Adherence despite feeling well	Even when you are feeling well, getting a check up is very important.	Even when you are feeling well, coming to clinic and taking your medicines is very important.
Side effects	You may notice changes in how you are feeling. Please tell us if you need help or advice.	You may experience side effects from your medications such as nausea or fatigue. These are also effects of pregnancy. These effects usually subside. If you are having challenges, don't stop your medicine.
Infant testing	Your baby will receive important vaccines and a check-up at the next visit.	Your baby will receive important vaccines and a test to make sure they are not infected at the next visit.

Table 3

Demographic characteristics of randomized controlled trial participants

	n (%) or median (IQR)
	N=825
Age (years)	27 (23-31)
Time since HIV diagnosis (years)	2.00 (0.08-5.00)
Primary education completed	634 (76.8)
Location	
Nairobi	306 (37.1)
Nyanza	519 (62.9)
Shares phone	245 (29.7)
Status disclosed to anyone with access to phone	640 (78.6)

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